

Full title: Perceived Positive and Negative Consequences after Surviving Cancer and their relation to Quality of Life

Brief running head: Perceived Consequences after Cancer & HRQoL

ABSTRACT.

Surviving childhood cancer has multiple implications on both physical and psychological domains of the individual. However, its study and possible effects on health-related quality of life (HRQoL) outcomes of adolescent survivors has been understudied.

The objective of this study was twofold; to assess positive and negative cancer-related consequences (psychosocial and physical) in a sample of adolescent cancer survivors and to explore their relationship with HRQoL outcomes.

Forty-one participants answered two questions about positive and negative consequences in the aftermath of cancer and filled in the KIDSCREEN-52 self-reported version. Data were analysed using mixed methods approach.

87.8% of the sample identified positive consequences and 63.4% negative consequences in survivorship. Four positive categories and five negative categories with regard to cancer-related consequences were found. *Changed perspectives in life* narratives seem to be the positive consequence more related to HRQoL (*physical well-being, mood & emotions, autonomy, social support & peers*), followed by *useful life experience* (*physical well-being, autonomy, social support & peers*). *Psychological impact* was the most referred negative consequence with a significant detrimental effect on *social support and peers* HRQoL dimension.

Even if the majority of survivors reported benefit finding in the aftermath of cancer, concomitant positive and negative consequences have been found. However, findings only reveal a significant relationship between positive narratives and HRQoL, and negative consequences do not seem to have a significant influence on overall HRQoL in survivorship.

KEYWORDS: Childhood cancer; Psychosocial consequences; Health-related quality of life; Adolescent survivors; Psycho-oncology.

Number of total words: 5.423

INTRODUCTION

A life-threatening illness such as cancer can challenge personal resources and trigger clinically significant distress (Stewart, Mishel, Lynn, & Terhorst, 2010). As it applies to cancer, distress is defined as a multifactorial unpleasant experience of an emotional, psychological, social or spiritual nature that, if excessive, could interfere with the individuals' ability to cope with cancer, its physical symptoms or even its demands with regard to the compliance of the treatment and medical advices (Stuber, Kazak, Meeske, & Barakat, 1998).

Focusing on survivorship, the last decade has witnessed an increasing interest in psychological distress research after cancer and, specifically, in posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms in childhood cancer survivors and their parents (Brown, Madan-Swain, & Lambert, 2003). This could be explained by the fact that the advances in cancer treatment have increased the number of survivors and consequently, the interest to understand how people cope with cancer. Additionally, since 1994 a cancer diagnosis has been included in the DSM-IV as one major trauma related to posttraumatic stress symptoms (American Psychiatric Association, 2000). Studies have shown that survivors often have elevated levels of distress (Ljungman et al., 2003) and may be at higher risk for post-traumatic stress disorder (PTSD) compared to siblings or a control group (Askins & Moore, 2008; Kamibeppu et al., 2010; Li, Chung, & Chiu, 2010). Larsson et al. (Larsson, Mattsson, & Von Essen, 2010) noted that PTSD symptoms tend to elevate over time, such that young adult survivors are at greater risk for PTSD symptoms than child or adolescent survivor groups. This is consistent with other studies that indicated a higher risk for psychosocial problems after treatment ends (Ljungman et al., 2003). However, other theoretical and descriptive accounts suggest that adolescents struck by cancer did not inevitably suffer negative consequences or develop posttraumatic stress reactions; moreover, they usually experience a number of good consequences of the disease in survivorship. So far, obtained results suggest that the vast majority of adolescent cancer survivors are able to report both positive and negative consequences as a result of the oncological experience, thereby adding to the complexity of the

cancer experience (Mattsson et al., 2007; Maurice-Stam, Grootenhuis, Caron & Last, 2007; Sundberg et al., 2009).

The identification of positive consequences from adversity has been commonly termed as benefit finding (Michel, Taylor, Absolom, & Eiser, 2010). This is defined as: *the fact to find benefits (or positive consequences) in personal, social, psychological and/or spiritual domains, after having suffered a trauma or having experienced a highly adverse situation* (Kinsinger, et al., 2006). Even though traditional psychology has focused on negative psychological impact after traumatic events, recently, with the rapidly increasing literature on positive psychology, more attention is paid to positive reactions and personal strengths in the face of stressful events (Alisic, Van der Schoot, Van Ginkel, & Kleber, 2008; Frazier et al., 2009; Joseph & Linley, 2006; Seligman & Csikszentmihalyi, 2000). A growing body of research on survivors of childhood cancer has documented the presence of benefit finding among this population (Currier, Hermes, & Phipps, 2009; Michel et al., 2010). Recent findings show that suffering cancer during childhood might enhance psychosocial function in survivorship (Servitzoglou, Papadatou, Tsiantis, & Vasilatou-Kosmidis, 2009). Specifically, some authors have found that in the extended phase of survival (>3-5 years free of cancer) survivors of childhood cancer report higher levels of vitality and lower levels of mood disturbances than a reference group of healthy comparable individuals (Castellano et al., 2009; Klassen, Anthony, Khan, Sung, & Klaassen, 2011). Similarly, some articles have pointed out that being exposed to cancer during adolescence might result in an acceleration of maturation, self-confidence and personal awareness expressed as increased emotional and social competence (Jörngården, Mattsson, & Von Essen, 2007; Mattsson, Ringnér, Ljungman, & von Essen, 2007; Parry, 2003; Servitzoglou et al., 2009). However, it must be taken into account that, in stark contrast to the research cited above, a nearly equal number of studies have pointed out the contrary. That is, having a cancer diagnosis during adolescence is related to long-term psychosocial dysfunctions such as peer-relationship difficulties, poor self-reported quality of life, worries about fertility, sexual dysfunction, fears about cancer recurrence or several limitations in performing some physical activities (Brown et al., 2003; Zebrack et al., 2002).

To our knowledge, most of the studies in this field have only described benefit finding and there is still few data regarding potential health correlates to this perceived impact among adolescent survivors of childhood cancer (Zebrack et al., 2012). Therefore, both negative and positive consequences should be considered when exploring possible correlates of health-related quality of life (onwards, HRQoL) among this population (Jörngården et al., 2007; Mattsson et al., 2007; Michel et al., 2010). HRQoL includes physical and mental health self-perceptions of the individual and their correlates; including health risks and conditions, functional status, social support and socioeconomic status (Ravens-Sieberer et al., 2005, 2008).

This cross-sectional mixed methods study is aimed to identify the extent to which positive and negative consequences are perceived among adolescent cancer survivors in the aftermath of cancer and to explore whether these perceptions are related to their current HRQoL. Given the lack of scientific knowledge in this field and the exploratory nature of this study, no specific hypotheses are stated.

METHOD

Ethical statement and Setting

Ethical approval was obtained from the reference hospital ethics committee board. Informed consent was obtained before participation from each participant after they have received an information sheet and oral explanations about the aims and characteristics of the study. The research complies with the Helsinki Convention norms and its' subsequent amendments. The whole study was carried out at the (name of the hospital and department).

Recruitment and sampling

Eligible adolescent cancer survivors were identified through the *Registro Nacional de Tumores Infantiles Sociedad Española de Oncología Pediátrica* (RNTI-SEOP) (Peris-Bonet et al., 2003). The RNTI-SEOP is a hospital-based central registry for all pediatric oncology centers and geographic areas of Spain. It was created to collect, process and provide data related to

pediatric oncology. All adolescents diagnosed with cancer and treated in the (name of the hospital and department) were identified to participate in the study. Inclusion criteria for study participation required that: (a) participants had been diagnosed with cancer (excluding CNS tumors in order to reduce bias due to possible cognitive impairment) after the age of 8. Survivors diagnosed after the age of 8 were chosen because of the need to ensure that the cognitive maturity of these patients was sufficient during cancer so that reliable memories of their illness and personal experiences could be obtained. (b) To be 13-20 years old at the time of the study, (c) to be off-treatment for at least one year at the time of the study, and (d) to have a follow-up appointment at the reference hospital between May 2009-May 2010. Survivors with psychopathology or intellectual disability diagnosed before the first primary oncological diagnosis were excluded from the study.

Measures

Socio-demographic and illness-related data

Socio-demographic data were obtained from the patient in a semi-structured interview. The data included: gender, age, educational attainment, nationality and residence. Illness-related data were collected from medical records. The data included: oncological diagnosis, type of treatment, bone marrow transplantation, relapse, second malignancy, age at the first diagnosis (in years), and time passed since first diagnosis (in years).

HRQoL

HRQoL was assessed with the [REDACTED] version of the KIDSCREEN-52 questionnaire (Ravens-Sieberer et al., 2005, 2008). The KIDSCREEN is a self-reported measure consisting of 52 items in 10 subscales: *Physical Well-being*, *Psychological Well-being*, *Mood & Emotions*, *Self-perception*, *Autonomy*, *Parent Relations & Home Life*, *Social Support & Peers*, *School Environment*, *Social Acceptance/Bullying*, and *Financial Resources*. Scores can be calculated for each of the ten dimensions. T-values (mean = 50, standard deviation = 10) and percentages are available for each country stratified by age and gender. Higher scores indicate better HRQoL. Time required to fill in the questionnaire is approximately 15-20 minutes. The questionnaire has

acceptable levels of reliability and validity. Cronbach's Alpha values ranged from 0.77 to 0.89 (Ravens-Sieberer et al., 2008).

Positive and negative consequences

Perceptions of positive and negative consequences in survivorship with regard to the whole oncological experience were asked by means of a semi-structured interview based on two items: 1) *Currently, which would be for you the most negative consequences of having had cancer?* And 2) *Currently, and in spite of all, have you obtained something good from the oncological experience you have been through?* Answers were transcribed literally.

Procedure

Survivors eligible for the study were contacted by telephone by one psychologist (CC). In this initial contact, they were informed about the purpose of the study and asked for participation. If they agree to participate, an assessment appointment at the hospital was scheduled. The assessment was conducted by the main researcher of this study (CC) in a hospital office in a 45-minute session. Oral and written information about the study and the purpose of the research were provided by the same psychologist (CC) the same day participants came to the assessment appointment. Anonymity was ensured in the same informed consent. If the adolescents were younger than 18 years old, parents were also asked to provide oral and written consent on behalf of the adolescent. Parents were requested to remain in the waiting room while the patient completed the questionnaires and answered the semi-structured interview. Written transcripts of qualitative data were obtained. The whole procedure (recruitment, initial contact, assessments) was conducted by the same researcher (CC).

Data analysis

Data were analysed using a mixed methods approach. First, the narratives of children were transcribed and categorized in parallel by two experts in traumatic stress and chronic diseases using two different approaches: a) content analysis of the data with no previous theoretical framework, and b) analytic induction considering the previous categorization

performed by Sundberg, Lampic, Björk, Arvidson, & Wettergren (2009). Both categorization methods were subsequently compared and a consensus was reached between the two experts checking the compatibility of the two resulting taxonomies ($K = 0.78$, for further information, please see tables 2 and 3). A final categorization was used to generate dichotomous variables (presence vs. absence of positive and negative consequences) in order to perform non-parametric (Mann Whitney's U) score comparisons using the KIDSCREEN-52 scores as dependent variables (raw scores), and calculate its effect size (Cohen's d). Calculations were carried for those consequences reported for at least 20% of the sample ($n = 8$, two negative categories with a low occurrence –*bodily impairments & dysfunctions* and *altered body appearance*– were not considered for these analyses, see table 5). All analyses were carried using SPSS version 19 (SPSS, Inc., Chicago, IL, USA). A 95% confidence interval was used for all analyses.

RESULTS

Participant's characteristics

During recruitment, 47 patients met inclusion criteria. Among them, 6 (12.77%) did not agree to participate. One of the patients (16.7%) argued lack of time, whereas four of the patients (66.6%) stated their desire of not to talk about cancer and their experiences. Finally, one patient (16.7%) did not show up at the assessment appointment in spite of having accepted at the first telephone contact. Ultimately, 41 survivors participated in the study. For an extend description of the sample see Table 1.

(Insert Table 1)

Qualitative analyses

Results of the qualitative analyses are shown in Tables 2 and 3. As it can be seen, four positive dimensions were obtained (Table 2): 1) Changed perspectives in life (meaning, priorities), 2) Positive self-perception (maturity, optimism, personal strength, enjoy), 3) Positive interaction with others & empathy, and 4) Useful life experience. On the other hand, five

negative dimensions were found (Table 3): 1) Bodily impairments & dysfunctions, 2) Limitations in activity & social participation, 3) Psychological impact & re-experiencing, 4) Altered body appearance, and 5) Time loss.

(Insert Tables 2 and 3)

Quantitative analyses

87.8% of the sample (n = 36) reported positive consequences and 63.4% (n = 26) negative consequences in survivorship (n = 13, 31.7% reported only positive consequences; n = 3, 7.3% only negative, n = 23, 56.1% both and n = 2, 4.9% none). As explained in data analyses section, patients were dichotomously scored according to the presence or absence of each qualitative dimension in their narratives.

HRQoL mean scores were within normative values (T-scores): *Physical Well-being* (M = 47.83, SD = 7.31), *Psychological Well-being* (M = 51.66, SD = 8.89), *Mood & Emotions* (M = 52.13, SD = 10.42), *Self-perception* (M = 47.79, SD = 6.03), *Autonomy* (M = 54.13, SD = 7.31), *Parent Relations & Home Life* (M = 51.14, SD = 9.33), *Social Support & Peers* (57.22, SD = 8.92), *School Environment* (M = 49.60, SD = 6.45), *Social Acceptance/Bullying* (M = 50.88, SD = 9.55) and *Financial Resources* (M = 51.25, SD = 9.06).

Table 4 shows the results regarding positive narratives and its relationship to HRQoL dimensions (raw scores). All statistical significant relationships ($p < 0.05$) and large effect sizes (> 0.50) were in the same direction, being the existence of a positive narrative a sign of higher scores in HRQoL. Within the *changed perspectives in life* narratives, statistically significant differences ($p < 0.05$) and large effect sizes (> 0.50) were found for *physical well-being*, *mood & emotions*, *autonomy*, and *social support & peers*. Similarly, *useful life experience* narratives were related ($p < 0.05$ and $d > 0.50$) to *physical well-being*, *autonomy* and *social support & peers* KIDSCREEN dimensions.

Table 5 shows the results of the negative narratives. Within the *Psychological impact* narratives, statistical significant differences ($p < 0.05$) and a large effect size (> 0.50) were found for *social support & peers*, being the absence of negative narratives related to higher scores in

HRQoL dimension. *Limitations in social participation* narratives only showed statistical tendencies ($p < 0.1$, $d > 0.50$) within *financial resources*. *Time loss* narratives didn't have any statistically significant correlate. All Cronbach's alpha values for the HRQoL were above 0.65 except for the Autonomy scale which was 0.47. Although results regarding the autonomy dimension have been considered and discussed in this study, they must be taken with caution and as preliminary and exploratory findings.

DISCUSSION

Although cancer is usually an important source of distress and it could be related to several psychological disturbances, our findings support the idea that it can also be a catalyst for positive consequences. Previous studies have pointed out the same (Servitzoglou, Papadatou, Tsiantis, & Vasilatou-Kosmidis, 2008; Zebrack & Zeltzer, 2003). In our sample, most of survivors reported positive narratives describing a deepened appreciation for life, the development of a positive self-perception or the feeling of being more mature and self-confident, as well as greater awareness of life purpose and personal relationships' value. In spite of these results, several negative consequences with regard to physical and psychological limitations were also reported. These negative narratives commonly included musculo-skeletal and movement related dysfunctions which impair the ability to perform desired activities (e.g., sports, leisure activities) or re-experiencing symptoms such as worries about the disease coming back, hospital anxiety and other impact on mood.

As compared to the categories made by Sundberg et al. (2009) we have not found any positive narrative regarding an increased interest in science. The few survivors who reported a higher interest in medicine describe their motivations in relation to the desire to help the others. (Thus, these narratives were included in the "*positive interaction with others & empathy*" category (see Table 6).. Several survivors used the specific word "empathy" to describe a concrete personal benefit learnt during their disease, which allowed them to have more satisfactory and enriching relationships. "" (The rest of the positive categories were practically the same to Sundbergs'. The same occurred regarding negative categories. Categories obtained

by us were the same as those obtained by Sundberg. However, we had to include two changes. The first one was to specifically include “re-experiencing” as a concrete type of psychological impact. Several negative narratives included this type of consequence when describing routine health check-ups at the hospital or other medical procedures. . The second change was to include the category “time loss” since many survivors stated that they felt that their lives were in a “stand by” during their cancer. The following statements illustrate this point: “. Although few studies have addressed these issues, some research has pointed out the evidence of isolation or socialization difficulties in childhood cancer survivors, as well a more negative body image perception and image concerns, and how all these variables can modulate adjustment outcomes (Fan & Eiser, 2009; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Pendley, Dahlquist & Dreyer, 1997).

Taking into account our results, we consider the categories (both Sundbergs’ and ours) a good starting point to explore perceptions of positive and negative consequences in adolescent survivors of childhood cancer.

With regard to the relationship between positive narratives and HRQoL, we have found that *changed perspectives in life* narratives showed statistically significant relationships with different physical and psychological aspects of HRQoL. In this sense, *physical well-being*, *autonomy*, *mood & emotions* and *social support & peers* dimensions of HRQoL are significantly increased among those survivors who reported a fuller appreciation of life, having changed values or priorities, or having acquired a more positive view of life. Similarly, narratives describing cancer as a somewhat *useful life-experience* have been related to better scores on *physical well-being*, *autonomy* and *social support & peers* too. These results could reflect an underlying re-conceptualization of own health and life priorities, that might include family and social relationships in general. Cancer is a major threat that implies to establish contact with one’s body and health status. It is possible that before cancer, most of adolescents have never thought too much about their own health or well-being, and when cancer occurs they start to notice what they could have lost. Worries about physical limitations, long-term sequelae, or other concerns about the disease coming back, might re-adjust the way adolescents think about

their physical condition or feel about their own well-being once they are in survivorship.

Similarly, *autonomy* and *social support & peers* aspects might be reinforced after cancer since they learnt to appreciate their ability to perform desired activities on their own, as well as to enjoy leisure activities with others. “

Although *useful life-experience* has shown similar significant relationships to *changed perspectives in life*, we have not found the significant relationship with “*mood & emotions*” HRQoL dimension. This could be explained because in some sense, *useful life experience*’ narratives are an extension, or even redundant, to *changed perspectives in life*’ narratives. We have found no relationship for *positive interaction with others* but, as expected, a tendency for *parent relations & home life*. Finally, *positive self-perception* showed a tendency for *school environment*.

As mentioned above (see Data analyses section), only those categories referred for at least 20% of the sample were considered to explore relationships to HRQoL. Therefore, we can only consider for discussion negative narratives referring to “*limitations in activity and social participation*”, “*psychological impact & re-experiencing*” and “*time loss*”. Thus, we have observed only one statistically significant effect; those survivors describing *psychological impact* (such as: re-experiencing, worries about the disease coming back, hospital anxiety, etc.) tend to score lower on *social support & peers*. It is reasonable to assume that feeling distressed by the memories of the disease or the concerns about their future health could hamper social relationships since it has a detrimental effect on mood and self-confidence (e.g., feeling different to peers, weak).

Limitations

Although our refusal rate to participate is low and this is a reference hospital to treat pediatric cancer which ensures certain representativeness of the sample, continued emphasis should be placed on larger samples via multicenter cooperation that might allow to better replicate these results within subgroups of this population (i.e. diagnosis groups, age groups, similar range of time since diagnosis, etc.) and also to compare the results with other pediatric samples of patients with severe chronic diseases. In our study, 20 survivors aged between 18-20

attending to follow-up appointments in the reference service, have been included in the analyses. Thus, some reports could be modulated for their specific developmental stage and results must be considered with caution. This sample may be too small to triangulate quantitative and qualitative results. For this reason we have tried to strengthen our analysis by including two complementary qualitative methods and, in the case of quantitative results, we used non-parametric tests reporting also effect sizes. Therefore, results have to be considered as preliminary and exploratory data

Furthermore, the absence of positive and/or negative consequences could not be based on the participants' denial of having experienced that consequence, but in their failure to spontaneously mention that they did experience it. Additionally, future research should try to study the psychological processing in front of challenging situations such as cancer, in order to clarify why some people could report positive consequences in the aftermath of cancer while others tend to have a more negative view, even with a better physical outcome. Some authors have proposed a repressive adaptation style to explain these outcomes (Aldridge & Roesch, 2007; Phipps, Steele, Hall & Leigh, 2001). This style could explain why some children report fewer negative consequences than they have actually experienced as a way of coping with difficulties and achieve good adjustment. In line with this argument, some research has pointed out that this style should not systematically be considered as a negative feature (e.g. not being aware of their symptoms or long-term difficulties) because data suggest that avoidant strategies could be adaptative in certain situations (Aldridge & Roesch, 2006; Phipps & Steele, 2002). However, this relationship requires further examination.

It is also important to try to reveal the association of distress (negative consequences) and growth (positive consequences) since it could have different clinical implications. Taking all these hypotheses as a whole, it is plausible to think that interventions aimed to alleviate distress do not necessarily facilitate growth, but more research is needed in this sense.

Conclusions

Concomitant negative and positive cancer-related consequences seem to go hand-in-hand in the aftermath of a trauma such as cancer during childhood. However, positive

consequences seem to be more frequent and correlated to overall HRQoL in survivorship when compared to negative consequences. Our results suggest that interventions to promote HRQoL might be focused on promoting positive consequences more than alleviate the negative ones. Although determining therapy focus, objectives and techniques are pending issues in paediatric psycho-oncology, a review in the field suggests that the effectiveness of such interventions could be improved if they are focused on patients' strengths, parents are involved and a flexible and a dynamic approach is considered throughout the different stages of the process (Muglia, Bragado-Álvarez & Hernández-Lloreda, 2014).

These findings can be of theoretical and clinical relevance to clarify the experiences and adjustment of adolescent cancer survivors. It is expected that these results would encourage further research in this field, in order to provide clinicians a clearer picture of adolescent cancer survivors needs and to guide them to carry out their psychosocial work with paediatric oncology care.

REFERENCES

- Aldridge, A. A., & Roesch, S. (2007). Coping and adjustment in children with cancer: A meta-analytic study. *Journal of Behavioral Medicine*, 30(2), 115–29.
- Alisic, E., Van der Schoot, T. A. W., Van Ginkel, J. R., & Kleber, R. J. (2008). Looking beyond posttraumatic stress disorder in children: posttraumatic stress reactions, posttraumatic growth, and quality of life in a general population sample. *The Journal of clinical psychiatry*, 69(9), 1455–61. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19193345>
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. (p. 943). American Psychiatric Publishing. Retrieved from <http://books.google.com/books?hl=en&lr=&id=3SQrtpnHb9MC&pgis=1>
- Askins, M.A., & Moore, B.D. (2008). Psychosocial Support of the Pediatric Cancer Patient Lessons Learned Over the Past 50 Years. *Current Oncology Reports*, 10, 469–476.
- Brown, R. T., Madan-Swain, A., & Lambert, R. (2003). Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *Journal of traumatic stress*, 16(4), 309–18. doi:10.1023/A:1024465415620
- Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical psychology review*, 26(3), 233–56. doi:10.1016/j.cpr.2005.10.002
- Castellano, C., Blasco, T., Oller, A., Pérez-Campdepadrós, M., Sánchez De Toledo, J., & Capdevila, L. (2009). [Quality of life in adolescent survivors of childhood cancer]. *Medicina clínica*, 133(20), 783–6. doi:10.1016/j.medcli.2009.04.034

- Castellano, C., Pérez-Campdepadrós, M., Capdevila, L., Sánchez de Toledo, J., Gallego, S., & Blasco, T. (2013). Surviving Childhood Cancer: Relationship between Exercise and Coping on Quality of Life. *The Spanish Journal of Psychology*, 16, E1.
doi:10.1017/sjp.2013.1
- Currier, J. M., Hermes, S., & Phipps, S. (2009). Brief report: Children's response to serious illness: perceptions of benefit and burden in a pediatric cancer population. *Journal of pediatric psychology*, 34(10), 1129–34. doi:10.1093/jpepsy/jsp021
- Frazier, P., Tennen, H., Gavian, M., Park, C., Tomich, P., & Tashiro, T. (2009). Does self-reported posttraumatic growth reflect genuine positive change? *Psychological science*, 20(7), 912–9. doi:10.1111/j.1467-9280.2009.02381.x
- Fan, S., & Eiser, C. (2009). Body image of children and adolescents with cancer: A systematic review. *Body Image*, 6, 247–56.
- Glaser, B. G. (1965). The Constant Comparative Method of Qualitative Analysis. *Social Problems*, 12(4), 436–445.
- Jörngården, A., Mattsson, E., & Von Essen, L. (2007). Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: a prospective longitudinal study. *European journal of cancer (Oxford, England : 1990)*, 43(13), 1952–8.
doi:10.1016/j.ejca.2007.05.031
- Joseph, S., & Linley, P. A. (2006). Growth following adversity: theoretical perspectives and implications for clinical practice. *Clinical psychology review*, 26(8), 1041–53.
doi:10.1016/j.cpr.2005.12.006
- Kamibeppu, K., Sato, I., Honda, M., Ozono, S., Sakamoto, N., Iwai, T., Okamura, J., Asami, K., Maeda, N., Inada, H., Kakee, N., Horibe, K., & Ishida, Y. (2010). Mental health among

young adult survivors of childhood cancer and their siblings including posttraumatic growth. *Journal of Cancer Survivorship*, 4, 303–312

Kinsinger, D. P., Penedo, F. J., Antoni, M. H., Dahn, J. R., Lechner, S., & Schneiderman, N. (2006). Psychosocial and sociodemographic correlates of benefit finding in men treated for localized prostate cancer. *Psycho-oncology*, 15(11), 954-961.

Klassen, A. F., Anthony, S. J., Khan, A., Sung, L., & Klaassen, R. (2011). Identifying determinants of quality of life of children with cancer and childhood cancer survivors: a systematic review. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 19(9), 1275–87. doi:10.1007/s00520-011-1193-x

Larsson, G., Mattsson, E., & Von Essen, L. (2010). Aspects of quality of life, anxiety, and depression among persons diagnosed with cancer during adolescence: a long-term follow-up study. *European journal of cancer (Oxford, England : 1990)*, 46(6), 1062–8. doi:10.1016/j.ejca.2010.01.021

Ljungman, G., McGrath, P.J., Cooper, E., Widger, K., Ceccolini, J., Fernandez, C.V., Frager, G., & Wilkins, K. (2003). Psychosocial Needs of Families With a Child With Cancer. *Journal of Pediatric Hematology/Oncology*, 25(3), 223-231.

Li, H.C.W., Chung, O.K.J., & Chiu, S.Y. (2010). The Impact of Cancer on Children's Physical, Emotional, and Psychosocial Well-Being. *Cancer Nursing*, 33(1), 47-54.

Mattsson, E., Ringnér, A., Ljungman, G., & Von Essen, L. (2007). Positive and negative consequences with regard to cancer during adolescence. Experiences two years after diagnosis. *Psycho-oncology*, 16(11), 1003–9. doi:10.1002/pon.116

- Maurice-Stam, H., Grootenhuis, M., Caron, H., & Last, B. (2007). Course of life of survivors of childhood cancer is related to quality of life in young adulthood. *Journal of Psychosocial Oncology*, 25(3), 43–58.
- Michel, G., Taylor, N., Absolom, K., & Eiser, C. (2010). Benefit finding in survivors of childhood cancer and their parents: further empirical support for the Benefit Finding Scale for Children. *Child: care, health and development*, 36(1), 123–9. doi:10.1111/j.1365-2214.2009.01034.x
- Noll, R. B., Bukowski, W. M., Davies, W. H., Koontz, K., & Kulkarni, R. (1993). Adjustment in the Peer System of Adolescents with Cancer: A Two-Year Study. *Journal of Pediatric Psychology*, 18(3), 351–364. doi:10.1093/jpepsy/18.3.351
- Parry, C. (2003). Embracing uncertainty: an exploration of the experiences of childhood cancer survivors. *Qualitative health research*, 13(2), 227–46. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12643030>
- Patenaude, Andrea Farkas, K. M. (2005). Psychosocial Functioning in Pediatric Cancer. *Journal of Pediatric Psychology*, 30(1), 9–27. doi:10.1093/jpepsy/jsi012
- Phipps, S., Steele, R. G., Hall, K., & Leigh, L. (2001). Repressive adaptation in children with cancer: a replication and extension. *Health Psychology*, 20(6), 445–51.
- Pendley, S. P., Dahlquist, L. M., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology*, 22(1), 29–43.
- Peris-Bonet R, Giner B, García A, et al. (2003) *Registro Nacional de Tumores Infantiles (RNTI-SEOP). Estadísticas básicas 4. 1980–2001. Supervivencia 1980–1997*. Valencia: Universidad de Valencia.

- Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., Auquier, P., et al. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert review of pharmacoeconomics & outcomes research*, 5(3), 353–64. doi:10.1586/14737167.5.3.353
- Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Power, M., Duer, W., et al. (2008). The KIDSCREEN-52 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research*, 11(4), 645–58. doi:10.1111/j.1524-4733.2007.00291.x
- Seligman, M. E., & Csikszentmihalyi, M. (2000). Positive psychology. An introduction. *The American psychologist*, 55(1), 5–14. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11392865>
- Servitzoglou, M., Papadatou, D., Tsiantis, I., & Vasilatou-Kosmidis, H. (2008). Psychosocial functioning of young adolescent and adult survivors of childhood cancer. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 16(1), 29–36. doi:10.1007/s00520-007-0278-z
- Servitzoglou, M., Papadatou, D., Tsiantis, I., & Vasilatou-Kosmidis, H. (2009). Quality of life of adolescent and young adult survivors of childhood cancer. *Journal of pediatric nursing*, 24(5), 415–22. doi:10.1016/j.pedn.2007.02.073
- Stewart, J. L., Mishel, M. H., Lynn, M. R., & Terhorst, L. (2010). Test of a conceptual model of uncertainty in children and adolescents with cancer. *Research in nursing & health*, 33(3), 179–91. doi:10.1002/nur.20374
- Stuber, M. L., Kazak, A. E., Meeske, K., & Barakat, L. (1998). Is posttraumatic stress a viable model for understanding responses to childhood cancer? *Child and adolescent psychiatric*

clinics of North America, 7(1), 169–82. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed/9894086>

Sundberg, K. K., Lampic, C., Björk, O., Arvidson, J., & Wettergren, L. (2009). Positive and negative consequences of childhood cancer influencing the lives of young adults. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 13(3), 164–70. doi:10.1016/j.ejon.2008.05.009

Taïeb, O., Moro, M. R., Baubet, T., Revah-Lévy, A., & Flament, M. F. (2003). Posttraumatic stress symptoms after childhood cancer. *European child & adolescent psychiatry*, 12(6), 255–64. doi:10.1007/s00787-003-0352-0

Zebrack, B. J., Stuber, M. L., Meeske, K. A., Phipps, S., Krull, K. R., Liu, Q., Yasui, Y., et al. (2012). Perceived positive impact of cancer among long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *Psycho-oncology*, 21(6), 630–9. doi:10.1002/pon.1959

Zebrack, B. J., & Zeltzer, L. K. (2003). Quality of life issues and cancer survivorship. *Current problems in cancer*, 27(4), 198–211. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12855951>

Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., & Robison, L. L. (2002). Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. *Pediatrics*, 110(1 Pt 1), 42–52. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12093945>